Liminality as a Dimension of the Experience of Living with Terminal Cancer

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ABSTRACT

Objectives: This paper is concerned with the phenomenology of death awareness within the context of being diagnosed with terminal cancer. The objective of the research presented in this paper is to provide a deeper insight into terminally ill cancer patients' engagement with their mortality.

Methods: The analysis presented here forms part of a wider project which involved conducting a metasynthesis of 23 phenomenological studies of the experience of living with the awareness of having terminal cancer published between 2011 and 2016.

Results: The metasynthesis identified four master themes which represent distinct experiential dimensions of living with terminal cancer. This paper focuses on one of these themes, *liminality,* in order to provide novel insights into the structure of death awareness whilst living with terminal cancer.

Significance of Results: The results suggest that *liminality* describes an experiential space from within which terminal cancer patients encounter a new relationship with their existence. Liminality offers opportunities for both connection (e.g. with the natural world) as well as disconnection (e.g. from loved ones and others who still have a future) and therefore contains the potential for suffering and distress as well as for joy and a sense of fulfilment. This understanding of liminality can help health care professionals provide psychological support for this client group.

KEYWORDS: liminality, living with advanced cancer; metasynthesis; death awareness, phenomenology of cancer

INTRODUCTION

Death awareness is a challenge that humans seem to have had to address throughout their recorded history. All religions and many of the cultural products that have been created by humans speak to our concern with mortality, and many different meanings have been given to the event of death (see The Lancet, 2005, for a precis of the major religions' perspectives on the end of life including Dorff, 2005, Keown, 2005, Markwell, 2005, and Baggini, 2005). Existential philosophers have proposed that whilst death awareness is perhaps the most significant feature of being human, we spend much of our time trying to avoid acknowledging that we will die (e.g. Heidegger, 1962). Terror management theory proposes that this is relatively easy to do when there are no reminders of our mortality but it becomes much harder when events (e.g. the death of a friend, a terrorist attack, a natural disaster) render our mortality salient (Greenberg at al. 1997). One event that renders one's own mortality particularly salient is to be diagnosed with a terminal illness. In this situation it is not just the reality of human mortality in general that suddenly looms large but one's own, personal mortality. Little and Sayers (2004: 191) differentiate between mortality salience which describes the awareness of "the shared eventual fate of mankind" and death salience which captures "an awareness of the inevitability, reality and finality of personal death and its nothingness". The latter constitutes a very personal challenge which is not easily dealt with.

This paper is concerned with the phenomenology of death awareness within the context of being diagnosed with terminal cancer.

Background

Medical innovations over the last 50 years or so have changed the way we die in the Western

world. Whilst previously sudden death, for example from a stroke or heart attack, was common, nowadays most people will have time to prepare for their death. Life-threatening conditions can often be treated or managed, and this means that people know that they are seriously ill for some time before they die from a disease. When death finally comes it will have been anticipated and prepared for in some way. This constitutes a significant change in our relationship with death and this transformation in the way we die is likely to have an impact on the way we live towards death.

In pre-modern times when death came quickly, people focused on strategies for 'helping the dead along their way' to ensure that the transition from this world to the next was made successfully (e.g. see Watkins, 2013). From the ancient Egyptians to Victorian Christians, the belief in an afterlife was widespread and almost universal (although, of course, sceptics always existed) and what seemed to be feared most was ending up in the 'wrong' place (such as hell or its equivalents) rather than death as the end of life itself. In large parts of the Western world people have lost the belief in the afterlife, and as a result fear death itself and focus on strategies which will ensure that they stay in this world for as long as possible. This focus on prolonging life (as opposed to preparing for the afterlife) has implications for the experience of those who come face to face with their own personal mortality and find themselves in a state of death salience (Little and Sayers, 2004).

Context

This paper is concerned with how people living with advanced cancer experience the living-dying interval during which they confront the 'existential paradox of living whilst preparing for death' (Coyle, 2006).

The analysis presented here forms part of a wider project which involved conducting a metasynthesis of 23 phenomenological studies of the experience of living with the awareness of having terminal cancer. Its objective was to gain a more complete understanding of the parameters of this experience and to provide a deeper insight into the lived experience of terminally ill cancer patients. The metasynthesis generated 19 theme clusters which informed the construction of four master themes (*trauma*, *liminality*, *holding on to life* and *living with cancer*) each of which captures a distinct experiential dimension of living with terminal cancer (Authors, 2018). The present paper focuses on one of the themes, *liminality*, in more depth and detail as this dimension of the experience of living with the awareness of having terminal cancer has important implications for the ways in which health care professionals can support this patient group. In the report of the findings of the metasynthesis as a whole (Authors, 2018), liminality could only be briefly introduced as the purpose of the metasynthesis as a whole was to map out experiential spaces available to people living with terminal cancer and to identify their defining features. However, we felt that the liminality theme deserves to be explored more fully as the existential challenge of death awareness can have a profound impact on patients' quality of life and yet, it is a neglected subject, perhaps because it involves an existential dimension to experience which can appear to be hard to nail down and address in concrete or practical ways. In this paper, we argue that a fuller understanding of the experience of liminality can help health care professionals identify interventions which have the potential to reduce psychological distress during this time.

With this in mind, the purpose of this paper is to unpack the meaning and experiential quality of inhabiting the liminal space and to give voice to participants as they describe their experiences of liminality, its tensions and inherent possibilities.

METHOD

The approach to metasynthesis taken in this research was informed by guidance provided by Bondas and Hall (2007) and Ludvigsen et al (2015). It seeks to offer novel interpretations of published research findings through their integration and to facilitate theory development rather than simply aggregating the results of existing studies.

The metasynthesis included studies that were published between 2011 – 2016, were based on semi-structured interviews and showed an explicit commitment to a phenomenological or hermeneutic method of analysis. Participants had to be at least 18 years old and were aware of their terminal diagnosis. Countries in which the study had been conducted comprised Australia, Israel, Norway, Taiwan, USA, Sweden, Denmark, Ireland, Thailand, Canada and the United Kingdom. The total number of participants across the 23 studies lies between 318 and 332 patients (due to the overlap of participants who generated data for some of the studies, the exact total sample size could not be determined). Participants were between 26 and 92 years old. They were suffering from a wide range of cancer types. A more detailed account of the methodology adopted in this study can be found in Authors (in press).

Thematisation and integration of the findings of the 23 studies generated theme clusters which were grouped into master themes which describe the parameters of the experience of living with the awareness of having terminal cancer. The remainder of this paper is concerned with one of these themes: *liminality*. This theme was composed of six theme clusters: impact on social life; separation; impact on the psyche; relationship to time; death; (un)certainty.

RESULTS

Master Theme *Liminality*

The term *liminality* (Latin for 'threshold') is used in anthropology to describe the quality of ambiguity and disorientation that arises as people transition from one sociocultural status to another (see Andrews & Roberts, 2015). The liminal stage is the middle stage of rituals of transition during which participants finds themselves in between their previous position (e.g. as a child) and their new position (e.g. as an adult). Within the context of cancer diagnosis, Little et al. (1998) have invoked the notion of liminality as a way of capturing the quality of suspension or detachment from the healthy world and its assumptions which, they argue, characterises cancer patients' experience of life post-diagnosis. According to Little at al. the encounter with cancer (regardless of its outcome) permanently changes a person's experience of themselves in the world, introducing an enduring sense of boundedness that comes from an awareness of limits to space, empowerment and time. Following Little at al. (1998) the notion of liminality has been explored in relation to cancer patients' experiences of finding themselves between categories of experience (e.g. following hormonal therapy for advanced prostate cancer, see Navon & Morag, 2004; Levy & Cartwright, 2015)

In the present metasynthesis the term *liminality* was used to refer to participants' accounts of their experience of inhabiting a space that is in between what was (i.e. their healthy lives) and what will be (their death/nothingness), a kind of twilight zone on the threshold of death. Participants emphasised that this transitional space cannot be shared with those who are healthy; inhabiting it separates the patient from the everyday world in which being alive is taken for granted. Descriptions of this experiential space had a bell jar quality as *liminality* is characterised by a sense of isolation and a loss of connection with the 'world of the living'.

The remainder of this paper provides the reader with a phenomenological description of the experience of liminality supported by quotations from participants across the 23 studies. This is followed by reflections on the clinical implications of the findings and some suggestions for improving psychological support for this client group.

The lived experience of l*iminality*

Participants described how facing their own death provided them with access to an entirely new perspective on life and a new awareness of what being alive means. They emphasized that this new perspective is only accessible to those who are facing death and cannot be shared with those who inhabit the healthy world. As one participant in Bentur et al's (2014: 4) study put it: "All my priorities and my perspective on life changed, I say those who haven't been there don't even understand what life is".

Participants described how their cancer had led them to feel increasingly detached from their previous social roles and how they felt positioned as outsiders, excluded from everyday life. This was partly the result of being physically unable to continue to take part in social activities and partly due to healthy others' discomfort with spending time with someone who is dying. Finding oneself in the liminal space means that one's experience cannot be shared with loved ones because they are perceived as being outside of that space. A participant in Saeteren et al.'s (2010: 815) study observed: "If I think of my folks at home, they say they understand but they don't. They have no basis for understanding."

Following a terminal diagnosis, a sense of separation from life sets in with, as Levy and Cartwright (2015: 1170) put it, "imminent death creating a shadow over their present self and separating them from the world of the living". Nissim et al. (2012: 368) characterised the liminal space as "an unfamiliar and terrifying land (which is) an unnatural place in which to live". Nissim et al.'s participants described finding themselves in this space as "a strange and almost indescribable experience, far from the familiar range of their experience and the experiences of those around them" (pp. 368-9). Participants referred to this experience as living on "death row", "with a time bomb" or "under a cloud (p. 369).

Liminality brings with it an altered relationship with time. Being suspended between the land of the living and the realm of death means it is difficult to sustain connections with either past or future as both of these lie outside of the bell jar that is the liminal space.

Finding oneself on the threshold of death creates a sense of 'living in wait' (Ohlen at al., 2013), whereby the unpredictability of the illness makes it impossible to plan and shape the future; instead, all the person can do is wait for what is to come next, be that test results, treatments, or ultimately death itself (e.g. Philip et al. 2014). According to one of Wiik et al.'s (2011:10) participants "The worst thing is to wait for the end to come… that's no life". To wait for things to take a turn for the worse, in a state of uncertainty regarding how and when this will be, is experienced as emotionally very challenging, generating significant amounts of anxiety.

We can see that the lived experience of the acute awareness of one's own personal death provokes feelings of disconnection, disorientation, isolation as well as anxiety.

Despite its challenges, however, being in the liminal space also makes new and precious experiences possible. The detachment from the everyday world with its daily hassles and its pre-occupation with the future allowed participants to fully appreciate the significance of the present moment and this can give rise to intense emotional and spiritual experiences. Basic sensory experiences (such as drinking a cup of coffee or smelling fresh flowers), enjoyment of sounds and sights (such as listening to music or being with nature) or religious practices (such as meditation or prayer) can generate an extraordinary sense of appreciation of being alive quite unlike anything the person has experienced before.

For example, one of La Cour and Hansen's (2012:130) participants refers to her appreciation of sensory experiences associated with activities like making jam as providing "ultimate fulfilment"; in relation to this experience she observes "And you don't need any more, do

you ?" . Another participant says "I like getting my fingers into things, I think it is so great to chop wood or paint something. I find it so wonderful to touch things" (la Cour & Hansen, 2012:131).

Singing in a choir was also identified as a context within which to access the "the sensory joy of really being alive and fully committed to experiences" (Levy & Cartwright, 2015:1172) as was the momentary relief of pain (Nissim et al. 2012: 374).

It seems that whilst in the liminal space people feel more able to respond to and resonate with the physical world around them, which can come as a (welcome) surprise. One participant in Levy & Cartwright's (2015:1172) described his experience of the physical world as giving rise to a "transcendent state":

> "Getting out into the physical world, going on the beach for surf. Solitary, on my own, astride a surfboard, all these beautiful natural forms and shapes and smells and sounds around you. And it just puts you in a … I don't want to sound a bit too stupid… but you know a transcendent state" (Robert)

One participant in Nissim et al.'s (2012) study invoked a graphic image of imminent execution during the French Revolution in order to emphasise the significance of the intensity of the present moment for those who are facing death :

> "I have this image of the French Revolution, these people who have been dragged to the guillotine screaming and in terror and the ones who just up the steps they go, head held high and they don't think about the fact that the world is going to end. They think about the fact that there's a wonderful moon outside and of course it is going to end but that time before is important" (p. 373)

The changed relationship with time that characterises the liminal space, therefore, gives new meaning to the present moment and, indeed, to the meaning of time itself. The foreclosure of

the future means that the present and its possibilities loom much larger. One participant in Willig's (2015:422) study describes her sense of time "expanding outward (…) in moments of extreme intensity" and how this feels like she is literally "stepping out of time".

Participants' changed relationship with time seems to be at the heart of their experience of liminality as it informs both their sense of separation from the world of the living (as a result of being unable to share in a future) and their ability to access the present moment in ways that those who (assume that they) have a future are unable to do.

DISCUSSION

Clinical Implications

It seems that the changed relationship with time that characterises liminality contains possibilities for both loss and gain. This results from a weakening of connections with the meaning and value of the everyday world and a simultaneous opening up of opportunities for a heightened sense of presence in the world. The latter can generate new and intense in-the-moment experiences based on sensory input. The experience of finding oneself in a liminal space provided participants with an opportunity to appreciate life on the basis of sensory and aesthetic experiences.

To assist patients in accessing the rewarding aspects of liminality health care professionals can work with patients to help them increase their sensory awareness in the here-and-now, as well as provide opportunities for patients to participate in activities that generate sensory and aesthetic experiences such as listening to music or spending time in/with nature (see La Cour & Hansen, 2012; Arman & Backman, 2007). Facilitating a focus on the here-and-now through engagement with sensory input enables patients to allow the present moment to expand and to gain access to a sense of fulfilment and joy. In those moments, patients step

out of conventional (linear) time and escape the yoke of the future focus that characterises everyday life [1] .Karlsson et al. (2014) suggest that in close proximity to nature patients can recover a sense of existential certainty despite their wider experience of existential uncertainty provoked by their terminal diagnosis. They recommend that care for patients with terminal cancer includes 'nature prescriptions' (p.7) which provide patients with access to experiences in/with the natural world. La Cour and Hansen (2012:132) encourage health care professionals to facilitate "enriching sensory experiences integrated in the daily activities and care giving for the dying person" in order to improve end-of-life care. We endorse these recommendations and would add that appreciation of the present moment can also be facilitated through animal-assisted therapy (Fine, 2010) or mindfulness practice (2013).

Study Limitations

There are reductive tendencies in metasynthesis research because the process of integrating findings from a collection of studies can have a homogenising effect and screen out differences (see Bondas & Hall (2007) and Weed (2008)). It is important to acknowledge that there were some notable differences in the findings of the studies included in the

[1] Here, we were reminded of the poet William Blake's (1803) words "To see the world in a grain of sand, And heaven in a wild flower, Hold infinity in the palm of your hand, And eternity in an hour". The same sentiment was expressed by one participant in Nissim et al.'s (2012) study: "I look out the window at the leaves… just to look at the leaves and see them is a justification for having been alive. It justifies the whole process" (p. 374).

metasynthesis and that not all participants in all the studies described experiences of liminality

Integrating the findings from the 23 studies involved a process of interpretation on the part of the researchers and it must be acknowledged that different researchers might have produced different interpretations of the material. Add to this the challenge of finding a balance between integrating findings across studies and preserving the unique features of each study's findings, and we have to accept that different researchers would have opted for more, or indeed less, streamlining of the results from across the 23 studies. Finally, there were some limitations to the search strategy for studies to be included in the metasynthesis which may limit the validity of the findings in that only systematic electronic searches together with a follow-up of references were used.

Conclusion

To conclude, the results from our metasynthesis suggest that *liminality* describes an experiential space from within which terminal cancer patients encounter a new relationship with their existence. Within this space, their connection with the everyday world of the living weakens whilst opportunities for a heightened sense of being alive open up. This suggests that liminality contains opportunities for both connection (e.g. with the natural world) as well as disconnection (e.g. from loved ones and others who have a future). It is, therefore, neither a 'positive' nor a 'negative' state of mind but rather an experiential space which contains the potential for suffering and distress as well as for joy and a sense of fulfilment. This understanding of liminality can help health care professionals provide psychological support for this client group.

REFERENCES

Arman, M. & Backman, M. (2007) A longitudinal study on women's experiences of life with breast cancer in anthroposophical (complementary) and conventional care, *European Journal of Cancer Care*, 16(5): 444-450.

Andrews, H. & Roberts, L. (2015) Liminality, *International Encyclopedia of the Social & Behavioral Sciences*, 2nd edition, volume 14. http://dx.doi.org/10.1016/B978-0-08-097086-8.12102-6

Baggini, J. (2005) End of life: the humanist view, *The Lancet*, 366: 1235-1237.

Bentur, N., Stark, D.Y., Resnizky, S. & Symon, Z. (2014) Coping strategies for existential and spiritual suffering in Israeli patients with advanced cancer, *Israel Journal of Health Policy Research*, 3:21. DOI: 10.1186/2045-4015-3-21

Blake, W. (1803) Auguries of Innocence. https://www.poetryfoundation.org/poems-and-poets/poems/detail/43650

Bondas, T. and Hall, E.O.C. (2007) Challenges in approaching metasynthesis research, *Qualitative Health Research*, 17: 113-21.

Coyle, N. (2006) The hard work of living in the face of death, *Journal of Pain and Symptom Management*, 32: 266-274. http://dx.doi.org/10.1016/j.jpainsymman.2006.04.003

Dorff, E.N. (2005) End-of-life: Jewish perspectives, *The Lancet*, 366: 862-865.

Fine, A.H (ed) *(2010), Handbook on Animal-Assisted Therapy. Foundations and Guidelines for Animal-assisted Intervenntions*, 3rd edition. San Diego: Academic Press,

http://dx.doi.org/10.1080/17482620701523777.

Greenberg, J., Solomon, S. and Pyszcznyski, T. (1997) Terror management theory of self-esteem and cultural worldviews: Empirical assessments and conceptual refinements. In: Zanna, M.P. (ed) *Advances in Experimental Social Psychology*, San Diego: Academic Press.

Heidegger, M. (1962) *Being and Time*. Trans. J. Macquarrie & E. Robinson. Oxford: Basil Blackwell.

Kabat-Zinn, J (2013). *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*. New York: Bantam Dell.

Karlsson, M., Friberg, F., Wallgren, C. & Ohlen, J. (2014) meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: A life-world phenomenological study, *BMC Palliative Care*, 13:28. http://biomedcentral.com/1472-684X/13/28

Keown, D. (2005) End of life: the Bhuddist view, *The Lancet*, 366: 952-955.

La Cour, K. & Hansen, H.P. (2012) Aesthetic engagements: "Being" in everyday life with advanced cancer, *American Journal of Hospice & Palliative Medicine*, 29(2): 126-133.

Levy, A. & Cartwright, T. (2015) Men's strategies for preserving emotional well-being in advanced prostate cancer: an interpretative phenomenological analysis, *Psychology & Health*, 30(10): 1164-1182.

Little, M., Jordens, C.F.C., Paul, K., Montgomery, K. and Philipson, B. (1998) Liminality: A major category of the experience of cancer illness, *Social Science and Medicine*, 47 (10): 1485-1494.

Little, M. and Sayers, E.-J. (2004) The skull beneath the skin: Cancer survival and awareness of death, *Psycho-Oncology*, 13: 190-198.

Ludvigsen, M.S., Hall, E.O.C., Meyer, G., Fegran, L., Aagaard, H. and Uhrenfeldt, L. (2015) Using Sandelowskiand Barroso's metasynthesis method in advancing qualitative evidence, *Qualitative Health Research*, 1-10, Doi: 10.1177/1049732315576493

Markwell, H. (2005) End-of-life: a Catholic view, *The Lancet*, 366: 1132-1135.

Navon, L. and Morag, A. (2004) Liminality as biographical disruption: Unclassifiability following hormonal therapy for advanced prostate cancer, *Social Science & Medicine*, 58: 2337-2347.

Nissim, R., Rennie, D., Fleming, S., Hales, S., Gagliese, L. & Rodin, G. (2012) Goals set in the land of the living/dying: A longitudinal study of patients living with advanced cancer, *Death Studies*, 36: 360-390.

Ohlen, J., Gustafsson, C.W. & Friberg, F. (2013) Making sense of palliative treatment. Its significance to cancer care communication and information provision, *Cancer Nursing*, 36(4): 265-273.

Philip, J., Collins, A., Brand, C.A., Moore, G., Lethborg, C., Sundararajn, V., Murphy, M.A. & Gold, M. (2014) "I'm just waiting…": An exploration of the experience of living and dying with primary malignant glioma, *Support Care Cancer*, 22: 389-397.

Saeteren, B., Lindstrom & Naden, D. (2010) Latching on to life: Living in the area of tension between the possibility of life and the necessity of death, *Journal of Clinical Nursing*, 20: 811-818.

The Lancet (2005), Volume 366, Numbers 9488,9489,9491, 9492, Viewpoint: End of Life

Watkins, C. (2013) *The Undiscovered Country. Journeys Among the Dead*. London: The Bodley Head.

Weed, M. (2008) A potential method for the interpretive synthesis of qualitative research: Issues in the development of 'meta-interpretation', *International Journal of Social Research Methodology*, 11(1): 13-28.

Wiik, G.B., Devik, S. & Hellzen, O. (2011) Don't become a burden and don't complain: A case study of older persons suffering from incurable cancer and living alone in rural areas, *Nursing Reports*, 1:e3, pp. 7-14.

Willig, C. (2015) "My bus is here": A phenomenological exploration of 'living with dying', *Health Psychology*, 34(4): 417-25.

Wilig, C. and Wirth, L. (2018) A metasynthesis of studies of the experience of living with terminal cancer, *Health Psychology*, 37(3): 228-237